

## What if I didn't sign up for notifications?

If you are part of the Registry and want to receive emails about research studies, you must change your account settings and agree to receive the emails. PALS who are not part of the Registry would need to join the Registry. If you have questions about the research trial emails, how to register to receive them, or how to join the Registry, please call us at **1-877-442-9719** or email us at **ALSSystemAdmin@cdc.gov** (Monday through Friday: 8am to 5pm ET).

## What's in it for me?

Finding and enrolling in trials and studies can be difficult. The Registry gives PALS a way to more easily and quickly

- find research studies they might be interested in, and
- connect directly with researchers for more information and/or to enroll.

By enrolling in the Registry and taking the risk factor surveys, PALS will also be helping scientists learn more about the disease.

## Is my personal information safe?

Yes, the Registry will not give PALS names or other personal information to researchers. The Registry will send you an email with information about the study and how to contact the researcher if you are interested in taking part.

## What kinds of studies are these and who is participating?

A description of the studies and what institutions are taking part can be found here: **<http://www.cdc.gov/als/ALSResearchNotificationClinicalTrialsStudies.aspx>**

**Be Counted.  
Fight Back.  
Make a Difference.**

# #ALS #BeCounted



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**U.S. Department of  
Health and Human Services**  
Agency for Toxic Substances  
and Disease Registry

# THE NATIONAL ALS REGISTRY



## Connecting Persons with ALS (PALS) with Researchers



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## What is ALS?

Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, is a disease that affects the nerve cells in both the upper and lower parts of the body. This disease causes the nerve cells to stop working and die. The nerves lose the ability to trigger specific muscles, which causes the muscles to become weak and leads to paralysis. Approximately 80% of people with ALS die within 3-5 years of diagnosis.

## What is the National ALS Registry?

The National ALS Registry, maintained and operated by the federal Agency for Toxic Substances and Disease Registry, is a congressionally mandated registry for persons in the U.S. with ALS (PALS). It is the only population-based registry in the U.S. that collects information to help

scientists learn more about who gets ALS and its potential causes. No one knows for sure what causes ALS and currently there is no cure. If you have the disease, consider joining the Registry and completing the brief risk-factor surveys because your answers could help scientists defeat ALS.

## What is the research notification mechanism?

Research is critical for helping scientists and PALS to better understand the disease. The Registry's research notification mechanism allows PALS to know about and directly connect with scientists who are conducting studies and clinical trials. Such research may lead to finding the cause(s), better treatment options and therapies, prevention strategies, and ultimately a cure for ALS.



## How do I participate?

When you enroll in the National ALS Registry, you will be asked if you would like to receive emails about research participation. When you choose to be notified about ALS research, the Registry will send you emails about new research studies and clinical trials that are recruiting people to take part in the study. The Registry will periodically only send emails about ALS research studies to Registry-enrolled PALS who agree to receive such emails. The Registry will not send PALS personal information to researchers. PALS will have to contact researchers directly to join or learn more about a study or clinical trial.

